

# End-of-life issues in advanced dementia

## Part 1: goals of care, decision-making process, and family education

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### Abstract

**Objective** To review the issues with setting goals of care for patients with advanced dementia, describe the respective roles of the physician and the patient's family in the decision-making process, and suggest ways to support families who need more information about the care options.

**Sources of information** Ovid MEDLINE was searched for relevant articles that were published before March 7, 2014. There were no level I studies identified; most articles provided level III evidence.

**Main message** For patients with advanced dementia, their families have an important role in medical decision making. Families should receive timely information about the course of dementia and the care options. They need to understand that a palliative approach to care might be appropriate and does not mean abandonment of the patient. They might also want clarification about their role in the decision-making process, especially if withholding or withdrawing life-prolonging measures are considered.

**Conclusion** Physicians should consider advanced dementia as a terminal disease for which there is a continuum of care that goes from palliative care with life-extending measures to symptomatic interventions only. Clarification of goals of care and family education are of paramount importance to avoid unwanted and burdensome interventions.

In Western countries, most people who reach the stage of advanced dementia die in long-term care (LTC) settings.<sup>1,2</sup> It is an incurable life-limiting illness for which palliative care is often appropriate.<sup>3</sup> Although familiar with palliative care in cancer, many family physicians and other practitioners might think they are not prepared for the specificities of palliative care in dementia, such as difficulties associated with diagnosing the terminal phase of the illness (prognostication), establishing goals of care, decision making when the patient cannot actively participate, and issues relating to communication with the family. In this article I present relevant concepts and ethical considerations. I also reflect on the decision-making process and on ways to educate families about therapeutic options. In a companion article (page 337) I will focus on symptom management and care issues at the end of life.<sup>4</sup>

### Case description

You are looking after Mrs M., an 85-year-old woman with advanced dementia. She was admitted to LTC 2 years ago and is now totally dependent with severe dysphagia and minimal oral intake. She is almost mute. Today she is feverish and tachypneic. You diagnose recurrent aspiration pneumonia clinically; you treated Mrs M. with antibiotics last month for a similar condition. The nurse expresses concern that she might also be dehydrated.

### EDITOR'S KEY POINTS

- Goals of care help ensure open and ongoing communication between the patient, proxy decision maker, family, and care team, so that all parties have a common understanding of what constitutes optimal care for the patient.
- For patients with very severe dementia, decisions are almost always made with the surrogate decision maker. To minimize the burden on surrogate decision makers, physicians should promote compassionate, evidence-based counseling and try to reach a consensus so that the decision is shared or agreed upon.
- Physicians should consider advanced dementia as a terminal disease for which there might be a continuum of care that goes from a palliative approach with acceptable life-extending measures to a symptomatic-only approach. Application of palliative care principles should guide communication about goals of care, and family education is of paramount importance to avoid unwanted and burdensome interventions.



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Mrs M.'s daughter wants to see you and has many questions: Why is her mother sick again? Is it poor care? Can you cure her? Should she be sent to the hospital? Is she near the end of life? Why are you talking about withholding antibiotics? Is that not euthanasia?

## Sources of information

This article reviews the literature on end-of-life care in advanced dementia. Ovid MEDLINE was searched for articles that were published before March 7, 2014, containing the following MeSH terms: *dementia* and *palliative care* or *terminal care* or *end-of-life* or *end of life*; *dementia* and *nursing home*; and *dementia* and *decision making*.

A total of 1041 abstracts including 29 review articles were retrieved.

The search was supplemented with a hand search and a review of related topics in the UpToDate database ([www.uptodate.com](http://www.uptodate.com)). Although there were a few longitudinal observational studies included, no level I studies were identified and most articles provided only level III evidence (ie, expert opinion and consensus statements).

## Main message

**Advanced dementia as a terminal illness.** Even if they can appreciate that dementias are progressive, incurable diseases, families and clinicians might have difficulty viewing them as conditions that cause death.<sup>5</sup> In LTC, *pneumonia*, *cardiac disease*, and *cerebrovascular disease* are most commonly listed as the cause of death on death certificates for patients with and without dementia. Most families and clinicians probably view the terminal event, often pneumonia or urinary tract infection, as the cause of death unrelated to dementia. However, people with advanced dementia develop apraxia, dysphagia, and decreased mobility, thus increasing the risk of infection, malnutrition, and other adverse outcomes. Therefore, advanced dementia should be considered a terminal illness, particularly at the very severe or end-stage state.<sup>6</sup>

**Prognostication.** The course of advanced dementia is one of progressive but often erratic decline. During the end stage of this disease, patients typically experience "sentinel events" (eg, eating difficulties, recurrent infections, hip fracture, stroke) that require decision making to direct care. Although predicting death in advanced dementia is difficult, aspiration pneumonia generally indicates a high risk of death in the next 6 to 12 months. One study showed that nursing home residents whose proxies had an understanding of the poor prognosis and clinical complications expected in advanced dementia were much less likely to have burdensome interventions in the last 3 months of life than were residents whose

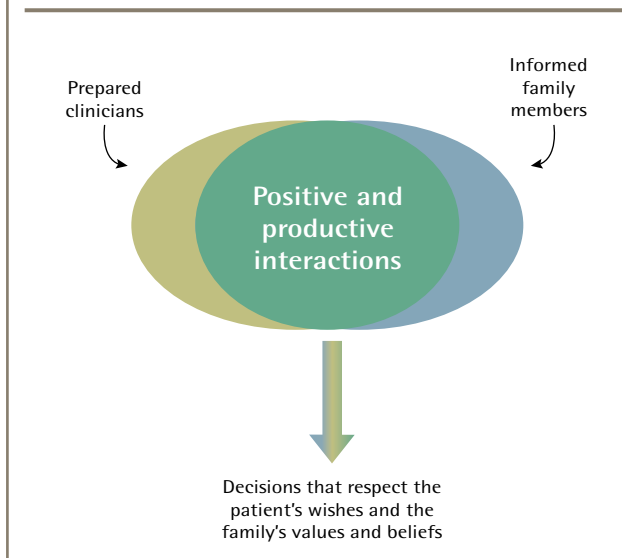
proxies did not have this understanding.<sup>7</sup> Prognostic tools exist but have a modest ability to predict death.<sup>8,9</sup> Therefore, in general, care provided to these patients should be guided by their goals of care rather than estimated life expectancy.

**Goals of care.** Goals of care are person-centred, culturally sensitive approaches to providing care that meet a patient's changing needs and respect his or her preferences regarding end-of-life care. Goals of care help ensure open and ongoing communication between the patient, proxy decision maker, family, and care team, so that all parties have a clear and common understanding of what constitutes optimal care for the individual patient. Toward the end of life, it is usually necessary to give priority to palliative care over potentially burdensome life-prolonging treatment.

When receiving palliative care, patients will often be treated for intercurrent or comorbid illnesses, such as urinary tract infections, pneumonia, or heart failure, along with their life-limiting medical conditions. The objective of such treatment is to reduce physical discomfort and maintain or improve well-being; however, the side effect might be that life is prolonged. As dementia advances, the question comes to the fore whether treatments of comorbid or new conditions might have life-prolonging effects that will expose the patient to intolerable symptoms related to the dementia. Thus, the focus gradually shifts from the quality of life to the quality of death and, at some point, life-extending side effects of medical treatments with a primarily palliative intention might be no longer morally acceptable. At that point, for example, it is appropriate to refrain from prescribing antibiotics for pneumonia and to relieve pain and dyspnea with a symptomatic approach only.<sup>10</sup>

**Decision-making process.** For patients with very severe dementia, decisions are almost always made with the surrogate decision maker owing to patient incapacity. It is the responsibility of the clinician to solicit and understand the patient's previously stated goals and values, and then guide and facilitate medical decisions so that the treatments provided are consistent with these goals and values. It is important to acknowledge that decisions to withdraw or withhold life-prolonging therapy might be particularly stressful for family members.<sup>11,12</sup> To minimize the burden of decision making for the surrogate decision maker, the physician should be prepared to promote compassionate, evidence-based counseling, and try to reach a consensus so that the decision is shared or agreed upon.<sup>13</sup> The ideal decision-making process is illustrated in **Figure 1**. **Figure 2** outlines the physician competencies that enable the decision-making process.

**Figure 1. Ideal end-of-life decision making when patients cannot participate**



Many factors influence the health care proxies and family members who participate in medical end-of-life decisions for patients with dementia.<sup>14</sup> The surrogate decision maker's perception of the patient's quality of life is one of the most important ones. When the quality of life is perceived as good, surrogate decision makers are more likely to accept interventions that prolong life. When it appears poor, symptomatic treatment without efforts to prolong life is more frequently chosen as the preferred goal of care. Other factors that influence goals-of-care preferences are the invasiveness of the treatment or investigation proposed, advance directives, the cultural and family context, and trust or distrust of the health care team.<sup>15</sup> For instance, if a trusted physician proposes that a palliative symptomatic approach might be more appropriate, his or her opinion might have more value than the opinion of an unfamiliar physician (eg, on-call physician). Understanding the family's perspective might help minimize conflicts between the family members

and the health care team. Most families will appreciate discussions in advance with the regular treating physician, before a crisis forces discussion to happen.

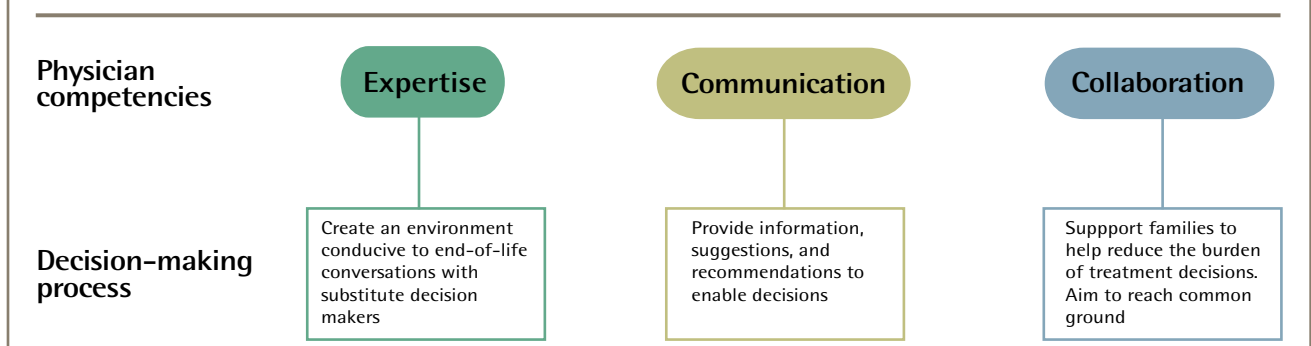
Physicians should be sensitive to ethnic variability in attitudes toward decision-making and end-of-life issues. They should make efforts to better understand the values and beliefs at stake. *Geriatrics Cultural Navigator* is a very useful free smartphone application developed by the American Geriatrics Society, which gives information about decision making, disclosure and consent, sex issues, and end-of-life or do-not-resuscitate decisions in various cultures.<sup>16</sup> However, clinicians should always be careful to not stereotype ethnic groups.

**Transfer to hospital.** Hospitalized patients with severe dementia frequently experience uncomfortable interventions that lack demonstrable benefit in this population and have poor prognoses despite aggressive care.<sup>7,17</sup> Iatrogenic illness is also common in patients with dementia who live in nursing homes. Nonetheless, families might choose to accept the burdens of hospitalization for patients whose primary goal of care remains life prolongation; in these circumstances, clear goals of care help ensure that appropriate treatments are provided in hospital.

When advance care planning results in palliative goals of care, hospital transfer is only appropriate when the treatment necessary to provide comfort is unavailable at the nursing home. For instance, admission for hip fracture might be justified even in late stages of dementia because surgery is usually the best treatment to control pain in this situation.

A do-not-hospitalize order is the explicit advance directive that limits the transfer of patients from the nursing home to the hospital setting. Such an approach does not always result in worse mortality or symptom control.<sup>18</sup> At the facility level, LTC homes with physician presence and on-call availability, nurse practitioners on staff, and higher staffing ratios are more likely to have directives to forgo hospitalization and be able to follow the directive in an acute situation.<sup>19</sup>

**Figure 2. Physician competencies that enable the decision-making process**



**Cardiopulmonary resuscitation (CPR).** Nursing homes differ in their policies toward CPR: some facilities provide on-site CPR; others contact emergency medical technicians with advanced life support training in the event of an arrest; a few nursing homes specifically state that they do not offer CPR. For patients with severe dementia, CPR is unlikely to be successful. Outside hospital, the chances of survival are low and CPR itself might be harmful and undignified. Even with the benefits of being in hospital, CPR is 3 times less likely to be successful (survival to discharge) in people with cognitive impairment than in those who are cognitively intact, and the success rate is similar to that found in people with metastatic cancer. Cardiopulmonary resuscitation attempts in unwitnessed arrests have an extremely low chance of success and, if successful, have a high risk of worsened function from hypoxia.<sup>20,21</sup>

**Withholding or withdrawing a life-prolonging treatment.** Patients, families, and physicians often struggle with the question of whether withholding or withdrawing treatment is equivalent to “killing” patients. From an ethical perspective, the 2 are readily distinguishable, as the motivation in each case is different. The goal in withholding or withdrawing treatment is to avoid inflicting a burdensome intervention (“letting go”), not to end the patient’s life. It is important to reassure family members that withholding or withdrawing life-prolonging treatment does not mean abandonment of the patient and that the focus will now be on “active” symptom management. Families might feel less guilty if they are told that low-tech, high-touch care will be provided (Box 1).


**Educating families about end-of-life issues.** Alzheimer’s Association—Greater Illinois Chapter has published a

booklet<sup>22</sup> intended to provide helpful information about ways to encourage and provide comfort care to people with dementia. This booklet could be given to families after patients’ nursing home admissions to help prepare them for end-of-life issues. Canadian researchers have also developed a guide for families of patients with dementia that can be useful for answering frequently asked questions about the trajectory of disease, clinical issues, the decision-making process, symptom management during the end of life in dementia, what to expect while the patient is dying, and grief.<sup>23</sup> Canadian and international studies have shown that the Canadian booklet is well accepted by families and practitioners,<sup>24–26</sup> and a pilot study suggests that the booklet improves communication between family and staff members, as well as satisfaction with care.<sup>25</sup> The booklet has been cited by the World Health Organization as an example of a better practice in the field of geriatric palliative care.<sup>27</sup>

## Case resolution

After your discussion with Mrs M.’s daughter, she acknowledges that her mother has a disease in its terminal stage. She understands that a palliative low-tech, high-touch approach is a relevant option. She appreciates your support during the decision-making process. However, she worries about controlling her mother’s symptoms. (Symptom management will be discussed starting on page 337).<sup>4</sup>

## Conclusion

Physicians should consider advanced dementia as a terminal disease for which there might be a continuum of care that goes from a palliative approach with acceptable life-extending measures to a symptomatic-only approach. Application of palliative care principles should guide communication about goals of care, and family education is of paramount importance to avoid possibly unwanted, futile, and burdensome interventions. 

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### Competing interests

None declared

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### Box 1. Symptomatic care in advanced dementia: the low-tech, high-touch approach.

Elements of the low-tech, high-touch approach include the following:

- Symptom control
- Mouth care
- Regular pain assessment with the appropriate tool (eg, PACSLAC)
- Comfort feeding
- Attention to dignity
- Frequent reassessments
- Comforting measures (eg, touch, music) by family and staff members who know the patient well

PACSLAC—Pain Assessment Checklist for Seniors with Limited Ability to Communicate.



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